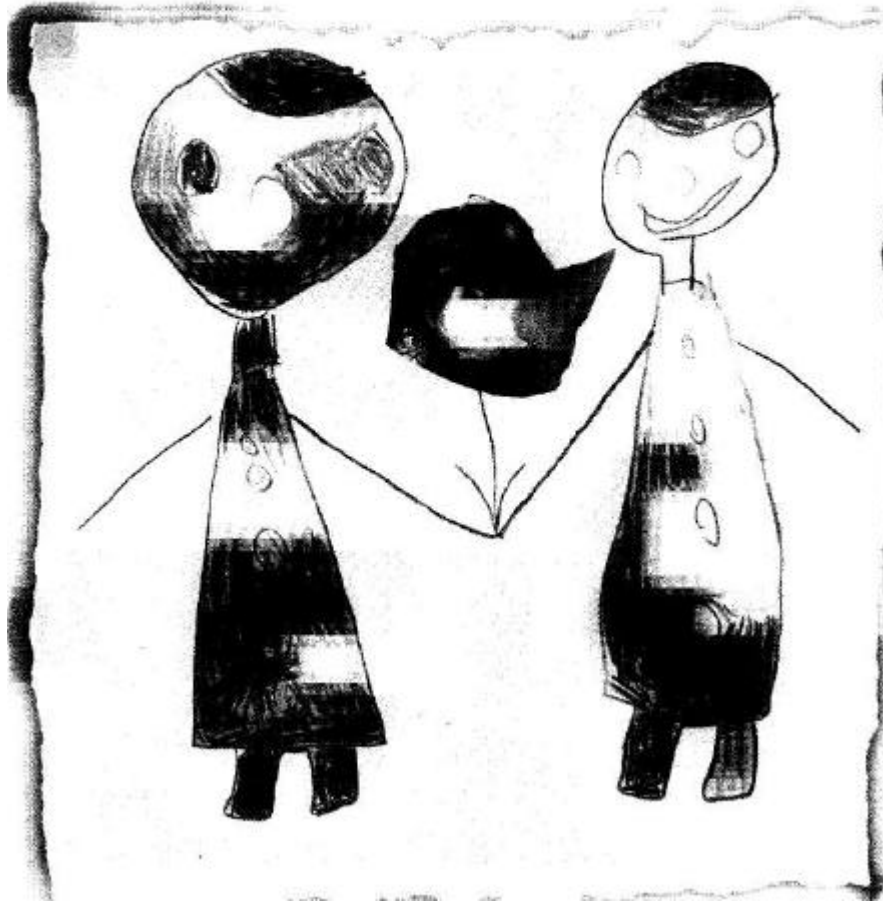


Barbara and Fred Grownups Now



Living Fully with Developmental Disabilities

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Chapter 14

Are We Better Off?

So are "we" — the thousands of persons in this country who either live with a family member with a developmental disability, who know one, or who have such a disability ourselves — better off than we were when we began our "civil rights" movement? The answer is both "Yes" and "No."

It is still an uphill struggle to create honest-to-goodness supports and inclusive communities for the Barbaras of this world — even here in the rich, progressive United States, and in the Golden State of California. But there *are* exemplary models to learn from and horizons to shoot for — *and persons* with disabilities who can by now teach us a thing or two, if only we will listen.

In 1978 The Presidents Committee on Mental Retardation published a report entitled, *Mental Retardation: The Leading Edge — Service Programs that Work*. First Lady Rosalynn Carter had requested such information and The President's Committee enlisted the talents of Robert and Martha Perske to describe and illustrate some of these programs. Bob scurried throughout the country to see for himself. The book charged me with great optimism, but also with the realization that my map for the future of our sons and daughters was still far from covered by such excellence. But, as Bob assessed the situation, "It's like parts of the car are all over the garage floor. All we have to do now is put them together."

According to projections made by the President's Committee on

Are We Better Off?

Mental Retardation at that time, the incidence of mental retardation could be cut in half by the end of the century if we practiced all we knew. If we could wipe out all layers of poverty, eliminate cultural deprivation, and provide love, security and care for all children, we would prevent many disabling conditions.

We *have* learned a great deal about pre-natal care, good nutrition, and prevention. For those families who already have a child with a developmental disability, genetic counseling is available for both parents and siblings. The mother can have an amniocentesis procedure and ultra-sound both of which diagnose certain abnormalities of the fetus inside the uterus.

I was thirty-five when I was pregnant with Barbara. I'm sure I would have availed myself of amniocentesis if it had been available in 1953, and if I had known that I was a mother at risk because of my age. But would I have chosen an abortion if I had been told of the possibility of an abnormality? It's impossible to second-guess a decision I did not have to make at the time.

It is precisely at this point that prevention becomes a difficult ethical question. Barbara is alive and a real person, and were I to have answered yes, it would have been like a retroactive death wish for a member of our family whom we love and value. Yet I firmly believe that biochemists and physicians will continue to ask why children are born with impairments, deformities and pathologies. They will continue to want to "prevent" these problems, in the dictionary sense of the word, to "forestall, hinder, keep from happening." I want the researchers to continue, for much as Barbara has deepened my awareness of the human condition and broadened my horizon, I also realize that she has been cheated of much pleasure, and I would have wished her a more trouble-free life.

Some of the young mothers of today are able to combine resignation to disability with high expectations. In the September 1996 *Networker*, a newsletter published by the Matrix Parent Network of California's Marin County, there is an article by Carol Gonsalves boldly entitled "Disability as a Part of Life." She writes:

When your child is diagnosed with a disability, whether it is at birth or later on, as a parent your life feels shattered, your heart aches in a way you never dreamed possible. That other parents share the same heartache seems quite removed. However, as we move forward and help our child be the best she can be, we begin to see how many other families and individuals are affected with disabilities. In fact, it becomes more apparent that disability is another fact of life, another variation in the human experience.

The experiences of parents are verified by statistical evidence. In a report by the California Birth Defects Monitoring Program, the largest analysis of birth defects undertaken, 1.6 million births between 1983 and 1990 were studied and little change in overall rates was found. This occurred despite an emphasis on prenatal care and widespread screening for two birth defects — Down syndrome and neural tube defects (spina bifida). In fact, birth defects are found to occur in one out of every 33 births. Teen mothers have an eleven percent higher risk for birth defects compared to mothers who are ages 20-29. It is also known that older mothers have a higher risk of having a baby with a birth defect.

So what does all this mean? It means that those who plan for our futures, who chart our medical paths, need to incorporate the knowledge that disability is a part of life. Whether it be legislators and government officials who negotiate provisions for special education or doctors and the medical community who oversee pregnancy, birth, childhood, and adulthood, disability must be viewed as part of who we are as human beings. Just as we plan for college, as we look to care for senior citizens, as we allow for differences in athletic ability, we need to make sure we plan to include those with disabilities "in the big picture" of our world. Birthday parties and playtime at the park, school projects and band class, vocational/career planning and weekends away, these are all activities in which those with disabilities can participate.

Ignoring the value of those with disabilities in all of the many activities in our communities, and assuming parents will terminate a pregnancy when it is determined that the baby has disabilities, these are all forms of discrimination. In our high speed rush to technological superiority and material preeminence, we must not forget who we are as people: individuals who come in

all sizes, colors, abilities, and interests. Disability is a part of life, and we are obligated to insure that this message is never lost.

A British co-worker of mine reached a similar conclusion: "Mental Retardation? that's just the way some people are." A perfect logo for school and community inclusion.

A brilliant young social worker studying for her law degree said to me, "If my disability (spina bifida) had been discovered by amniocentesis they might have killed me."

Twenty-five years ago we were just beginning to receive information on medical research that might throw light on the causes for our children's medical conditions. At a state convention of parent associations, we were told by genetic experts that they had come up with new identifiable chromosomal information on mental retardation. They were encouraging us as "high risk" families to make use of this knowledge. Al and I decided to have a chromosomal study done which might throw some light on the cause of Barbara's condition. Her file referred to it simply as "etiology unknown."

If there was one thing Barbara hated, it was needles, but in our fervor to advance the cause of science we went ahead. This put us in the position of trying to explain to her why she had to let the doctor take some blood out of her arm and send it to the lab. We didn't want to say that there was something wrong with her or that we wouldn't want Karen or David to run the risk of having a child like her. But she had let us know that she was aware of her problems with speech, physical coordination and reading, so we told her that the blood test might tell doctors why she had these problems, and then they might be able to help new babies grow up without them. Barbara seemed to accept this explanation, but the tests showed no chromosomal abnormalities.

The Association for Retarded Children (which later changed its name from Children to Citizens and is now called The Arc), and those of us who belonged to it, eagerly continued to work for the cause of medical research. From small local chapters to state organizations up to national headquarters, we made significant financial contributions to medical research each year at convention time, and

spread the word about new-found knowledge. Then we used all possible political muscle to push for and demand preventive measures.

I especially remember the annual State Convention of 1968 when Dr. Richard Koch was President of the California Association. He was at the time a practicing professor of pediatrics and strong advocate for our children. He spoke to us of his research on PKU (phenylketonuria), a metabolic disease in which a faulty gene causes a build-up of the amino acid phenylalanine (contained in all protein foods like milk and meat) in the blood of the baby. This failure of the body to handle protein will result in serious mental retardation and autism by the age of three if not immediately treated with a stringent diet. Dr. Koch explained that the test could be done by drawing a single drop of blood taken from the heel of a newborn. Then he urged us to "hit the pavement" and talk to our local physicians about this. At first we protested that as lay-person-parents we wouldn't get past the receptionist without explanations in hand. If I remember correctly we subsequently received such factual information. Then we did go out to tackle our local doctors, and the "heel test" for PKU is now being done routinely for all newborns in the United States and Canada. Stringent diet for the first eight years of life was shown to inhibit developmental delays.

But medical research on PKU has not stood still. Barbara Dolan, Nurse Counselor for Genetics of Redwood Coast Regional Center, the center for our four-county Northern California area, tells me Dr. Koch has continued his work on PKU and has made life saving new discoveries. He has found evidence that some of the PKU babies who were allowed to go off the special diet at eight years of age are showing increased levels of phenylalanine in adulthood with disturbing symptoms. The thought of resuming the distasteful diet which overshadowed their childhood is frightening but necessary. It is especially necessary and doubly scary for women who are pregnant, because, if their phenylalanine level has risen to abnormally high levels, it may endanger the fetus.

Dr. Koch, Barbara Dolan, and Christina Bekins, a nutrition consultant, are now jointly preparing a paper on treatment interventions

Are We Better Off?

for those persons of advanced age who were never tested for or treated for PKU as babies. The two examples of their study are women in their upper fifties who have significant developmental disabilities and are developing additional symptoms extremely difficult to manage for those who take care of them. But even at this late stage in their lives they are showing great improvement with dietary intervention and social/psychological support.

Dr. Koch continues his work as participant in the Division of Medical Genetics at Children's Hospital of the University of Southern California in Los Angeles. He has recently made it his mission to locate former PKU patients and alert them to these new developments in order to prevent problems in a new generation of babies.

Parents have continued their personal involvement in other prevention issues. We pushed for stricter regulations and greater awareness of the dangers of lead poisoning, and the urgent need for a full range of immunizations for all children. These trojan efforts made a difference in early diagnosis and intervention, and have improved the quality of life for children. The attitude of society has changed because of our early efforts. More people truly believe that these babies' lives will be worth living — and that they will be valued — as it should be. That is progress, and as members of a parent movement we can take pride in it.

All these medical research efforts have gradually led us from the relatively narrow term "mental retardation" to the broader "developmental disabilities." It's still a tongue twister for some people, but is based on practical observations. "Mental retardation" can take many shapes, and encompasses a wide range of conditions from mild "slow learning" that is hardly noticeable, to severe combinations of medical diagnoses that overlap in treatment and interventions, thus "developmental disabilities" became the umbrella term. It was developed in the Congressional Kennedy-Yarborough bill, and was to include Cerebral Palsy, Epilepsy, later Autism and other neurological disorders that can benefit from similar programs. At the time individual advocacy organization worried about losing their hard fought identities and fi-

nancial support by the broadened terminology. We tended to be parochially protective of the boundaries of our advocacy efforts.

Personally I hoped this might lead to the Scandinavian approach that I had experienced, and which in the early seventies was focused on specific needs, regardless of diagnosis. A wheelchair was a wheelchair, and made available whether the person needed it temporarily for a ski fracture, or for a life with severe cerebral palsy. Sadly we still haven't streamlined our efforts. California's definition of developmental disability is different from the federal one. The federal definition is based on "daily living functioning," while in California we base eligibility for services on categorical diagnostic categories. It's confusing and persons with problems do fall between the cracks.

But parents do not give up. They have created wonderful oases which Bob Perske eloquently described in 1978 in his *The Leading Edge* report. He stoked our optimism and resolve to become the first line of defense for our children.

Take for instance an ideal situation. A baby is born with a disability. Help is available right after the baby is born because medical and nursing personnel have been well trained in counseling parents. Instead of postponing the discussion or glossing over the problem, the physician gently but honestly breaks the news to both mother and father. There is no longer any talk of placing the baby out of the home to spare the siblings. At this moment both parents may be incapable of understanding scientific explanations, but they can feel warmth and caring.

Enter Pilot Parents. They have been there themselves. They have been trained to listen, to comfort, and to know available resources. If the newborn has been diagnosed as having Down Syndrome parents can meet young persons who have that condition, who can explain how it feels and describe what they themselves have accomplished. The new parents will be able to place trust in future supports and resources in their community. The team approach begins. I know of one father who almost immediately after the birth of his child, picked up the phone and joined such a support organization.

The Leading Edge described examples of situations that made my

Are We Better Off?

own problems with Barbara seem insignificant. One couple, parents of a profoundly handicapped son and two teenage daughters, founded a home here in California called the Somerset Home School. It became a twenty-four hour training unit for six severely handicapped youngsters. The father and mother were administrator and program director and they employed four child care workers. Their home had access to the services of a physical therapist, nutritionist, case workers from the California Regional Center of their area, and a registered nurse. It became far more than a place where services were delivered. According to *The Leading Edge*:

Frail, multi-handicapped children come into a three-acre wonderland of sensory stimulation and the reinforcement of healthy responses to it. The house is filled with bright colors, harmonious music, restful waterbeds, voices with loving tones, hands that massage, arms that hold one close, the stimulating waters of a Jacuzzi whirlpool, the smell of bread and a noisy canary. Outside is the sun, fresh air, a swimming pool, two spirited horses, a gentle pony, goats, dogs, cats, a rabbit and a duck. All play an important part in giving direction to these children's lives.

The training program itself was intense:

Detailed interventions of Neurodevelopmental Training are carried out faithfully. For example, body positioning and head control programs continue all day. The jerky infantile reflexes — so important at birth but an impediment to growth if they fail to diminish — are helped to fade, while the purposeful use of lips, tongue and jaw are stimulated and reinforced... All efforts are geared to helping the children move from weakness to strength, from negative behaviors to purposeful interactions with the world around them. Their progress is measured by precision charting of behaviors, as well as by monthly videotapes.

The aim of Somerset Home School was to provide every appropriate early childhood intervention and to involve the family increasingly so that a stronger, more valued child would return to his or her own home. In his glowing report on the program Robert Perske cast a vote for parental action:

There is hope for the mentally retarded [1978 language] when

the parents of such children refuse to accept what others believe about their handicapped child. In this case, a family has ignored the pessimistic presumptions that profoundly handicapped children must be written off as having no future at all... Salvaging destinies is a supremely difficult business but it can be done.

The Leading Edge became a yardstick for me. Perske's book assured me that the programs I dreamed of for Barbara and her friends actually existed out there. That there were others who, regardless of the severity of their children's disabilities and level of functioning, believed they were worthy of excellence.

It has been eighteen years since *The Leading Edge* was published, and I had often wondered what happened to the Somerset Home School and the family who founded it. Did they still exist? Would their work still be an inspiration to parents? So I picked up the phone. The family's story has taken a sharp turn. Their marriage ended in divorce. Their son with severe disability lived to be nine years old, but the seed core of dedication remained intact in the mother. Her two daughters are grown and married, and as she says, "They are both wonderful mothers." She herself has become trained in the Waldorf method of education, and now that she is remarried, has founded another *Somerset School* with her new husband. At present it is a day school but they plan to enroll two live-in students. Again the school is located on many acres of beautiful land with all the stimulation of animals, gardens and water, as before. The school is staffed by trained Waldorf teachers and privately funded. The students have a range of learning disabilities, but are not as severely disabled as those in the previous school. Vitality, energy and joy were in her voice as we talked, and I was convinced that her and her husband's work comes under the "YES" column of my "are we better off?" question. Though she is not connected with our State of California's Developmental Disabilities System, she *is* bettering the lives of children with special needs. Robert Perske can be proud of her.

The Leading Edge also covered prevention, early intervention, infant stimulation and home training for parents. Infant stimulation included motor, language, and play activities which help a child "learn

Are We Better Off?

to move" so that he and she can "move to learn." We had stumbled on to the right track in our own attempts at stimulation for Barbara and I wish we had done more.

Perske's book reminded me of our own family's early start. We had been so lucky living in a friendly, rural community, complete with two parents, two siblings, good neighbors close by and a circle of friends. *Respite*— the chief ingredient in care for a child with developmental problems was then, and still is now, hard to come by and frequently missing. We were lucky to have had it.

It is inexcusable and discouraging that parents are still having difficulties in launching respite programs. There is an expressed need for this service, and I consider it the cornerstone of success of community programs, but at times it is the families themselves who are reluctant to ask for it. I have thoughts about the reasons why. Frequently the service agencies are responsible when they fail to let parents know respite is available. That's unconscionable. But parents may be too proud to ask. They are stuck in the stiff-upper-lip-do-it-yourself philosophy until something in the family constellation cracks. Both parents may be holding jobs. The pressure of all the activities which are focused on the child with special needs becomes overwhelming. Nobody smiles anymore. There seems to be no time for picnics or weekend outings. No one talks about Little League or soccer. And for the married couple it's goodbye to dancing, bridge or dinner out with friends. Even a normally relaxed sex life may seem unattainable.

I vividly remember the day I decided Karen and David were old enough to keep an eye on Barbara while I took a bath with the door closed. It was a memorable occasion. And I met a mother who had finally managed to enroll her little girl in public school in her neighborhood. I heard her burst out, "Goodbye advocacy! Hello world!" and she went on to say that she had just signed up for an art class at the junior college. Hers is just one small example of the creative energy that can be released in families through respite, and that is why it is so vitally important. It enables families to lead as normal a life as possible before stress, tensions and fatigue undermine relationships. Respite support should be offered freely to those who need it. Nobody should

be made to feel guilty about asking for it. In time, such a family may become a pillar of strength for others. I am learning in my own "third age" that asking for help can be a sign of strength.

The most visible changes in public services since Barbara was a little girl — and still the most controversial — are in the areas of education, employment and access to essential locations in home communities. Even in my glummost moments I can take comfort in that.

In education we survived the hard-fought era of "mainstreaming" which enabled our children to attend school on regular campuses, though not truly integrated into classrooms or activities with their peers. It was the trailer-at-the-far-end-of-the-campus-syndrome. The opposition by teachers and administrators to the concept was based on the fear of overloading already top heavy class size. That was understandable. The parents of the other children feared (and unfortunately many still do) that "their bright kids" would be short-changed in the learning process by the presence of "ours." But there were some school district administrators who got it. They realized the process would take time. They spent hours in meetings with teachers and parents preparing them for the concept that all children *can* successfully go to school together. In those districts the process became a smooth transition. Now that we can see children are capable of accepting each other with their differences and schools are learning about reasonable accommodations, we are on the high road to *inclusion*.

I take comfort in the laws we have managed to pass to bring about these changes. Today's family whose child has developmental problems can stand squarely on U.S. public laws.

The Education for All Handicapped Children Act was passed in 1979. It was succeeded by IDEA, the Individuals with Disabilities Education Act. Its reauthorization has just been accomplished by Congress, after many months of honest bipartisan struggle, some compromise, and participation by patient and hardworking parent and advocate leaders. For many families the struggle may not be over, but we can score one more on the side of "better-off."

The joys of school inclusion have come too late for Barbara, but in spite of this I take heart when I see the well trained and committed

teachers of her generation who have chosen special education as their field of work — some because of their early association and friendship with Barbara when they were children together many years ago. The little girl who first asked me why Barbara couldn't go to junior high with her, is now a certified counselor in one of California's Regional Centers. She loves her work and I'm proud of her. Another young woman who grew up with Barbara in our own circle of friends forty years ago is teaching students with severe disabilities in another state. I see articles in journals based on surveys of high school students who remember their elementary school days in classes where students with disabilities were included. They experienced it as a valuable lesson in diversity that they needed to grow into thoughtful adult citizens and change agents. We the parents can count on them as future allies.

Another giant piece of federal legislation spells hope for all citizens who are affected by disabling conditions. It is the ADA or Americans with Disabilities Act. It too is a federally mandated "rock" to stand on, but it will take continuing vigilance as it "wobbles" under attacks and accusations by those who consider it too expensive to implement. The ADA not only concerns itself with physical access and accommodations such as ramps and curb cuts, lowered kitchen sinks, wider bathroom doors, and accessible public transportation, it provides access to employment for the thousands of well qualified citizens with disabilities who are now waiting to make a contribution to the world of work *as their right*.

Al and I had realized early in Barbara's life that she understood what money is for, and that work is reimbursed with it. When Al brought home papers to be collated or stapled, she would help — and also ask to be paid. But before the Americans With Disabilities Act was signed into law by President Bush in 1990, segregation still operated in the workplace. Persons with disabilities were limited to long-term sheltered work with routine, repetitive chores. This didn't do much for their self esteem and sometimes brought out behavior that was inappropriately belligerent or even self-destructive. This contrib-

uted to the public's continuing stereotypical view of our people as *incapable*.

The passage of the ADA led all of us advocates a step up the ladder of acceptance. At the ceremony of the signing, Senator Tom Harkin of Iowa said:

With the passage of ADA, we as a society make a pledge that every child with a disability will have the opportunity to maximize his or her potential to live proud, productive and prosperous lives in the mainstream of our society.

Again the full impact of ADA was late for many of our adult sons and daughters. It did however affirm a lesson I had learned earlier from a used car dealer who had agreed to employ as a car washer a young man from the sheltered workshop. Several weeks had gone by when the vocational counselor dropped by the lot to inquire about his client. "How is Jim Walsh doing?" he asked the boss.

"Jim Walsh? I don't seem to recall—"

The counselor's heart sank. "You know, the young man I placed here from the workshop to try out for the car wash job."

"Oh yeah — Jim — I remember now. He's doing okay. He's one of us now."

Many more examples of excellence are by now scattered around Perske's "garage floor" and speak for growing acceptance of the diversity of our country's population. A community redevelopment program in Los Angeles was so successful it continued well after the federal grant which launched it ran out in 1977. It consisted of a crew of young men with developmental disabilities and a lead worker. According to one lead worker, "Some of the fellows take home blueprints and spread them out on the kitchen table to show their dads what they're doing. They may not be able to read the words, but they can point out the various components of the project and describe them. For some of the workers this has been the first time their fathers ever took an interest in anything they did." According to the project's director, "We've learned never to underestimate the personal values that come from wearing a tool belt, a hard hat and having one's own

Are We Better Off?

tool box. These items tell others that a guy stands ready to perform no-nonsense labor that can even be dangerous."

There were other private businesses, bravely founded by parents, that became commercially successful. A Donut Shop in southern California and a lunch counter take-out shop in Fresno set examples and spawned new concepts. Gradually many former "clients" of sheltered workshops have become "employees." They have grown in strength and courage and learned to speak for themselves. In the early days very few parents believed this could ever happen. We thought "we" would forever have to speak for "them," but this has radically changed. The young people have found their voices. *People First* has gradually evolved as a forceful organization.

I will not here attempt to write the history of the self advocacy movement. It has become another beacon of hope for parents — another answer to our perennial question of "what will happen to our sons and daughters after we are gone?" My own mentor, Gunnar Dybwad and his colleague Hank Bersani, have published *NEW VOICES, Self-Advocacy by People with Disabilities*, which records the growth of the organization — both in our country and internationally. It is expertly reported by Dybwad and Bersani, with poignant testimony by the people who have lived the life of disability.

I first learned about *People First* from the childhood friend of Barbara's who had moved to Washington State. She told me full of excitement about meetings she had attended which were organized and attended by persons with developmental disabilities. This seemed to me like a logical extension of the Youth ARC group here in California — the young volunteers and camp counselors whose enthusiasm and energy had so impressed me. I had heard them say that they did not want to be described as "serving the retarded," or "working for them." They wanted to be seen as working *with* them. So the next step had now been taken. Those with developmental disabilities were beginning to take their fate into their own hands. By the end of the seventies *People First* groups had formed in California, and I attended their first convention in San Francisco. It was a total "upper."

I had no idea Barbara would be there with her housemates and was